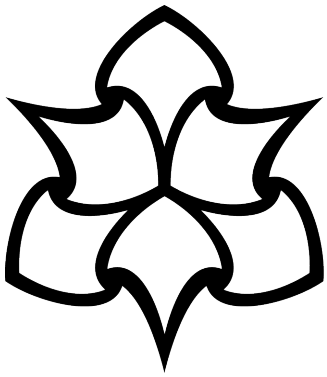

Black and ethnic minority carers perceptions on mental health services and support in the United Kingdom: a systematic review

Eula Miller, Stella Foluke Bosun-Arjie and Mandu Stephen Ekpenyong

Abstract

Purpose – *The purpose of this study was to examine and synthesise the empirical evidence on the perceptions of Black and Ethnic Minority (BAME) carers views on mental health (MH) services and support offered in the UK.*

Design/methodology/approach – *A comprehensive search conducted by searching Medline, Cumulated Index to Nursing and Allied Health Literature and Psychology and Behavioural Sciences Collection served to identify relevant studies that explored the perceptions of BAME carers on MH services. Other key sources and reference list of identified journal articles were searched to ascertain that this review contains all relevant studies and captured studies not indexed in the databases. Using the Critical Appraisal Skills Programme tool, 20 relevant studies published between 1996 and 2020 retrieved were and reviewed. From the reviewed papers five themes emerged which summarised the perception of BAME carers views on MH services and support services offered in the UK.*

Findings – *Critical appraisal of 20 studies that met the ascribed inclusion criteria was undertaken. A total of 18 studies were of qualitative design, one used a quantitative approach and one was a systematic review. Several themes addressing the participants' views were identified from the studies. The core themes central to these studies were: awareness and utilization of available MH services, language barriers to accessing MH services, positive experience whilst in contact with MH services, negative experience whilst in contact with MH services and difficulties in seeking help.*

Research limitations/implications – *One of the review criteria was to focus on peer-reviewed articles; grey literature was exempted from the search for relevant studies. Although a systematic literature review was conducted, there is the possibility that some appropriate studies were not identified. This could be because of different use of key terms in some of the studies. Papers that identified and acknowledged BAME MH carers and MH services were focused on, which resulted in 20 eligible studies for synthesis.*

Originality/value – *This review revealed the perception of BAME carers on MH services and available support offered. It highlighted that a significant number of BAME carers had limited understanding of the range of available MH services and support on offer within the UK. The review highlighted that fear of stigmatisation, discrimination in conjunction with the formulaic nature of MH services, delayed at best and inhibited at worst BAME Carers from accessing support from MH services, which consequentially had detrimental effects on service users receiving the timely appropriate support needed (Mermon* et al.*, 2016). It is, therefore, a recommended imperative that MH services are deliberate in their endeavour to be inclusive, culturally embracing and accessible, if the MH needs of diverse ethnic minority groups within the UK are to be met appropriately.*

Keywords *Mental health, Minority, Ethnic, Asian, Carer, Black*

Paper type *Literature review*

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Introduction

The Office of National Statistics (ONS, 2020) estimates that the UK population of England and Wales, Scotland and Northern Ireland is 66.8 million with approximately 16% of them

being non-White people. A significant number of Black, Asian and Ethnic Minority (BAME) who constitute the UK population has experienced various forms of inequalities and marginalisation. As reported by the King's Fund (2021), inequalities are revealed in areas of health income, unemployment and housing for BAME group. For instance, on income, 29% of Black, 20% of Asian, 26% of mixed groups are more than twice as likely to live in households with persistent low income than the White group. BAME group disproportionately died from COVID-19 in comparison to their White counterparts in the UK (King's Fund, 2021).

The Public Health England (Public Health England, 2018) acknowledged that social determinants of health, such as education, housing and employment, drive inequalities in physical and mental health (MH). Cummins (2018) added that austerity and associated policies have combined to increase the overall burden of mental distress and marginalisation within the UK. Regardless of the cause(s) of inequality, it is evident that inequalities and marginalisation increase the vulnerability of the BAME group to developing MH issues (Grey *et al.*, 2013). BAME groups are more likely to be diagnosed with a MH problem, be admitted to hospital with a MH problem, experience poor outcomes from treatment, disengage from mainstream MH services and have a poorer experience of relationships with MH service professionals (Grey *et al.*, 2013; Baker, 2017; PHE, 2019; Gov.UK, 2020)

Across the UK, increased frequency of abuse, self-harm and thoughts of suicide were higher among BAME women groups during the COVID-19 pandemic (Iob *et al.*, 2020).

MH services designed for BAME in the UK were reported to improve MH outcomes of the people (Vahdaninia *et al.*, 2020). In light of accessing MH services, an analysis of seven-year post MH services available to BAME group revealed a significant underrepresentation of referrals from the BAME population compared to the White population (Subramaniam *et al.*, 2020). It is imperative to first explore the perceptions of BAME MH carers on MH services and support in the UK. Therefore, we conducted a systematic review (SR) to seek evidence towards holistic understanding of how BAME carers perceive MH services and support in the UK.

The objective

A SR was conducted to synthesise the empirical evidence for a holistic understanding of how the BAME carers perceive MH services and support in the UK.

Methodology

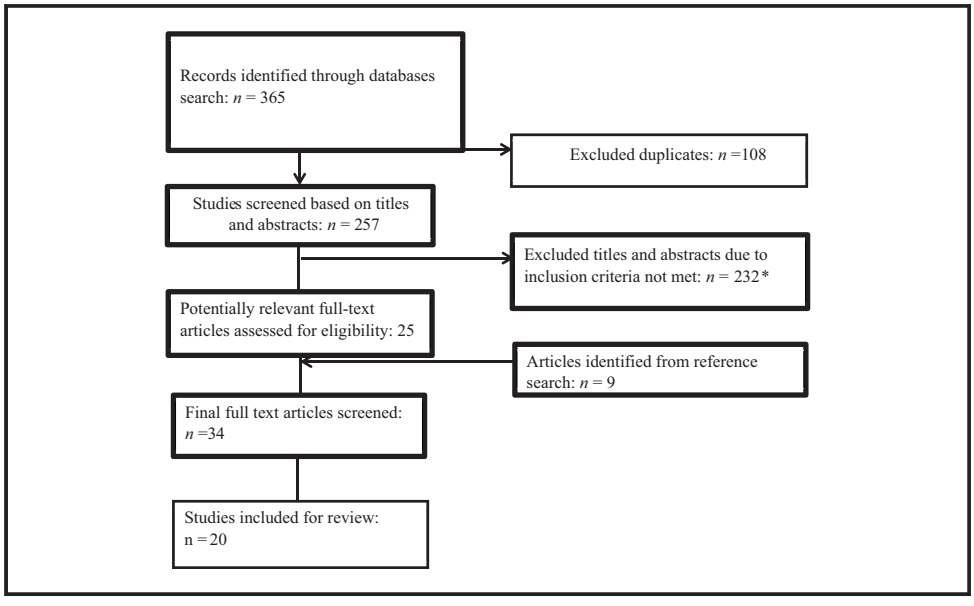
Data sources and literature search strategy

Literature from three databases Medline, Cumulated Index to Nursing and Allied Health Literature and Psychology and Behavioural Sciences Collection were searched to identify relevant articles for review. The search was conducted from January 1996 and December 2020. The search terms used included "BAME, BME, Black, Asian, ethnic minority," "MH," "carer* or caregiver*" and "experience or perception or attitudes or views" using "AND, OR" Boolean operator where necessary to combine. The combination of these key terms including MeSH terms was searched in the article's abstracts, titles and keywords. Please see Figure 1 for the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines (Moher *et al.*, 2009, 2015) (Table 1).

The rationale for using studies of UK BAME carers' perspectives was to ensure that the relevance and critical insight into the nature of the issue was fully understood in the country of origin where the authors of this work undertake their professional practice.

For quality assurance, the Critical Appraisal Skills Programme tool was used to facilitate the critical review of 20 eligible studies.

Figure 1 Flowchart showing the selection process of the included studies (p. 4)



Data extraction A total of 20 retrieved articles were reviewed individually and assessed using a data abstraction form to examine important information for emerging themes relating to the aim of this review. The extracted data include the name of the first author, publication year, aim, methodology, participant age, gender, study population, study design, study location, sample size and data collection method. Table 2 shows the summary characteristics of the included studies.

Findings

Data synthesis

These studies used in-depth semi-structured interviews or informal focus group discussions as the method of data collection. Six studies used a qualitative design. Sample size ranges from 5 to 175 participants.

Findings

The findings of this SR highlighted the following themes: the perception of carers on awareness and utilisation of available MH services, language barriers to accessing MH

Table 1 Eligibility criteria

Inclusion criteria	*Exclusion criteria*
■ Articles on perceptions of BAME carers perspectives on MH services and support within the UK ■ Articles published between 1996 and 2020 published in English ■ Qualitative, quantitative and systematic reviews	■ Articles on BAME carers of individuals with physical health conditions only, editorials, news brief, meeting abstracts, letters and correspondence, thesis, unpublished work, non-peer-reviewed studies and non-UK based studies

Table 2 Characteristics of included studies in the systematic literature review (p. 5)

S/n	*First author's name, publication year, study location*	*Aim*	*Study design; methodology*	*Gender*	*Data collection method*	*Study population; participant age, sample size, ethnicity*
1	Hatfield (1996) Milltown, UK	To explore the experience of Asian people about acceptability and appropriateness of MH services	Quantitative approach	14 Females 5 Males	Questionnaire	Asian Bangladesh 19 family members/carers
2	Greenwood *et al.* (2000) London, UK	To explore the experience of Asian people about mental illness, treatment and mental health services	Qualitative approach Grounded theory	7 Females 3 Males	In-depth interviews	Age range: 23–65 years (Indian origin) 10 Asian carers
3	Bowes and Wilkinson (2003) Scotland, UK	To explore the perception of dementia among older South Asian people as well as their families and carers and to investigate central issues of service support	Qualitative approach Thematic analysis	Females Males	Discussions and semi-structured interviews	Age range: not reported 4 South Asian families and carers Pakistani and Indian
4	McLean *et al.* (2003) UK	To explore the perception and interaction of African Caribbean mental health treatment and promotion	Qualitative approach Grid coding method		Interviews and focus groups	African Caribbean 30 participants in total including five carers
5	Keating (2004) Birmingham and London, UK	To demystify the consequences of the circle of fear that is perceived to cause the lesser treatment of African and African Caribbean adults in MH services	Qualitative approach	A mix of both men and women	Focus groups	Age range: 30–74 years 4 African 15 African Caribbean 19 participants
6	Adamson (2005) London, UK	To investigate the experience of caring for an older family member with emphasis on ethnic minority caregivers of people with dementia	Qualitative approach Grounded theory	Gender: not reported	In-depth semi-structured interviews	Age range: not reported 15 South Asian 21 African Caribbean 36 participants
7	Mackenzie (2006) Northern English city, UK	To explore the support needs of family carers from Eastern European and South Asian groups	Qualitative approach Grounded theory	Not reported	Semi-structured interviews	Age range: not reported 11 Pakistani 5 Indian 1 Polish 1 Ukrainian 18 Participants
8	Lawrence (2008) South London, UK	To investigate the caregiving attitudes, experiences and needs of family carers of people with dementia from the three largest BME groups in the UK	Qualitative approach Grounded theory	25 Females 7 Males	In-depth interviews	Age range: 33–87 10 Black Caribbean 10 South Asian 12 White British 32 participants

(*continued*)

Table 2

S/n	First author's name, publication year, study location	Aim	Study design; methodology	Gender	Data collection method	Study population; participant age, sample size, ethnicity
9	Jolley (2009) Wolverhampton, UK	To understand dementia within BME groups and how to improve relevant services	Qualitative approach Not reported	Not reported	Interviews	Age range: not reported 10 African Caribbean 20 South Asian 30 participants
10	Jutlla (2013) Wolverhampton, UK	Exploring Sikh carers caring for an older person with dementia	Qualitative approach Not reported	Not reported	Interview	Age range: not reported 5 Sikh 5 participants
11	Jutlla (2013) Wolverhampton, UK	Exploring migrant Sikh caregivers experience of caring for an older person with dementia	Qualitative Grounded theory	9 Females 3 Males	2–3 narrative interviews	Age range: not reported 12 Sikh 12 participants
12	Botsford (2011) London, UK	Exploring the experiences of partners of people with dementia in two ethnic minority population	Qualitative approach Grounded theory	6 Females 7 Males	In-depth interviews	Age range: 60–80 years 7 Greek Cypriot 6 African Caribbean 13 participants
13	Mukadam (2011) London, UK	To explore the link between attitudes to help-seeking for dementia and the help-seeking pathway in minority ethnic and indigenous groups.	Qualitative approach Thematic analysis	13 Females 5 Males	Semi-structured interviews	Age range: 27–85 years 4 White 5 Indian 5 Black 1 Irish 1 White 1 Chinese 1 Asian 18 participants
14	Koo (2012) Manchester and Leeds, UK,	To explore the experience and response of British Chinese to unipolar and bipolar depression	Qualitative approach Manual content indexing analysis technique	2 Females 12 Males	Semi-structured interviews	Age ranges: 41–70 years 14 carers Hong Kong Macao Mainland China British Chinese
15	Rabiee (2013) Birmingham, UK	To explore the perception of using and providing mental health services from the perspectives of black African and black African Caribbean mental health service users, their carers and voluntary services	Qualitative approach Krueger's framework and Rabiee's guidelines	Females Males	15 Telephone interviews 20 individual face-to-face 12 focus group interviews	Black African and Black African Caribbean

(*continued*)

Table 2

S/n	*First author's name, publication year, study location*	*Aim*	*Study design; methodology*	*Gender*	*Data collection method*	*Study population; participant age, sample size, ethnicity*
16	Rabiee (2014) Birmingham, UK	To explore the knowledge and experience of accessing mental health services among adult African and African Caribbean Service users and carers	Qualitative approach Krueger's framework and Rabiee's guidelines	14 Females 10 Males	9 focus groups 4 individual in-depth interviews	24 carers 9 African (Somalians and Congolese) 15 African Caribbean
17	Islam (2015) Birmingham, UK	To explore the cultural appropriateness, availability and acceptability of psychosis services in enhancing care experience and outcomes for BME patients	Qualitative approach Thematic approach and framework analysis	8 Females 3 Males	Focus groups	Mean age: 42 years 11 carers 5 Black British-Caribbean 3 British Pakistani 2 Black/Black British-African 1 Other
18	Parveen (2017) North of England, UK	To investigate the views of dementia and use of services among British Indian, African and Caribbean and East and Central European communities	Qualitative-inductive thematic analysis		Informal discussion groups	62 British Indian (6 groups) 50 African and Caribbean (5 groups) 63 East and Central European (8 groups)
19	Baghirathan (2018) Bristol, UK	Exploring the experiences of carers for family and friends living with dementia from South Asian, African-Caribbean and Chinese communities in Bristol	Qualitative-grounded theory	78 Females 25 Males	27 interviews with family carers Eight focus groups with 76 participants 9 African-Caribbean 7 South Asian 11 Chinese	47 individuals from different South Asian communities including Muslim, Hindu and Sikh 31 individuals from the Chinese community 25 individuals from African-Caribbean community 16 interviews with staff or volunteers at BAME-led VCSOs
20	Watson *et al.* (2019) UK	A systematic review of ethnic minority women's experiences of perinatal mental health conditions and services in Europe	Systematic review	A total of 15 articles were included in the review	All the included studies included women from a range of minority ethnic backgrounds and were all undertaken in the UK	Women from a range of minority ethnic backgrounds living in the UK

services, positive experience whilst in contact with MH services and negative experience whilst in contact with MH services and finally difficulties in seeking help.

Awareness and utilization of available mental health services. Some carers expressed their negative experiences about the un-nuanced approach to support that the MH services provided as well as the lack of continuity and unreliability in information and support received specifically post-acute hospital admission. Jolley *et al.* (2009) reported that the lack of confidence and belief in the expertise of existing MH services to meet the need of BAME service users was linked to the perceived inability of support services to understand and address issues of cultural diversity. Language barriers and feeling culturally stereotyped fostered distrust in the therapeutic alliance between service users, carers and health professionals. Carers believed that medical practitioner's knowledge was under-developed leading to high cases of misdiagnosis and delays in accessing relevant MH care support and services needed. Additionally, information insufficiency about the eligibility criteria for accessing available support to MH services was not given, consequently causing avoidable delays in accessing much-needed support. Watson *et al.* (2019) reported that some women were fearful of accessing support as they felt identification of their MH symptoms may result in them being judged to be a bad mother or that their children would be removed from them.

Mukadam *et al.* (2011) revealed that carers lacked trust and confidence in available MH services. The lack in confidence was because they believed that professionals would sometimes prematurely offered a diagnosis but were not as forthcoming in explaining the range of interventions, treatment and support on offer or needed to meet mental or social health care need (Mukadam *et al.*, 2011). This leads to insufficiency in support and information given. Such factors impacted the caring role, causing undue stress for both service user and carers. In addition, carers reported that their self-imposed "sense of familial responsibility "and the preconceptions of health professionals that BAME families care for "their own" also impeded access to available MH services in a timely fashion.

Parveen *et al.* (2017) acknowledged that the BAME groups that participated in the study relied on the family, social workers and their general practitioners (GPs) for support. However, the participating groups recounted the scarcity of cultural sensitivity support and GPs lack of awareness of culturally appropriate resources added to their plight when seeking support. Correspondingly, Islam *et al.* (2015) declared that lack of knowledge and understanding of the carers about the available MH services debarred and delayed their utilisation. Bowe and Wilkinson's (2003) study reported that carers desperately required assistance, but they lack access to proper MH services and support. In addition, Hatfield *et al.* (1996) reported that the lack of knowledge about the availability of MH services among some of the participants meant that the acuity of illness was worse when they eventually presented to and accessed services

Language barriers to accessing mental health services. Misunderstanding BAME carers' beliefs in conjunction with their lack of understanding of how to navigate health systems and access to services resulted in lower uptake of the existing MH services (McLean *et al.*, 2003). Watson *et al.* (2019) stated that for women to seek support they had to overcome cultural expectations that they would not discuss personal issues outside the family home. Additionally, other issues identified related to longer waiting times, lack of child care, domestic responsibilities, travel costs and the time of day services hindered BAME women accessing perinatal MH support.

Greenwood *et al.* (2000) and Koo (2012) found dissatisfaction and concerns about the interpreters and translators used in the MH services for BAME women. Koo (2012) highlighted language as a major barrier to effective engagement and communication with the health practitioners causing medical inaccuracies and resulting in service users and carers feeling disillusioned and disempowered when navigating MH services.

Positive experience whilst in contact with mental health services. Rabiee and Smith (2014) revealed that BAME carers valued the excellent support they received from the MH services and the favourable experience had when engaging with third sector agencies who appeared to be more culturally aware and provided nuanced care as regards to medication matters. BAME carers identified the lack of education on prescribed medication added to their distrust and non-compliance with medication regimes. In addition, "a model of good practice" of a specific MH service in the study area was reported in McLean *et al.* (2003). Good qualities highlighted include paying attention to individual needs, which differs from the supposed depersonalisation of the MH service users, enlightening users about the existing MH problems and services and incorporating into the MH services conversation about exclusion issues and cultural identity. In addition, Greenwood *et al.* (2000) acknowledged that carers appreciated the effective treatment and medication the patients received whilst being cared for as inpatients within hospital.

Negative experience whilst in contact with mental health services. Significant negative experiences were reported by a number of researchers (Bowe and Wilkinson, 2003; McLean *et al.*, 2003; Keating and Robertson, 2004; Baghirathan *et al.*, 2018; Rabiee and Smith, 2013; Rabiee and Smith, 2014).

Keating and Robertson (2004) carers reported a delayed response and attention from their local MH services when needed. Additionally, carers perceived the existence of a resistive dynamic of power between them and the MH practitioners, which prevented them from contesting any evaluations and decisions made by the practitioners. As well, carers felt they needed to be quiet during any consultation with the practitioners to avoid their relative being incarcerated or receiving a negative care response. Carers perceived MH services as demeaning and alienating, which evoked a considerable level of fear (Keating and Robertson, 2004). Racial discrimination of black people in the society was reported (Keating and Robertson, 2004).

McLean *et al.* (2003) reported that African Caribbean carers and service users identified "social exclusion" as an unremarkable racial experience they always encounter whilst in contact with the MH services. Many of the participants believed that it was imperative to create an atmosphere that is positive towards cultural identity and shift away from the historical-cultural ideology and individuality that happened during the era of slavery since this affected the way they interacted with the MH services and causes misdiagnosis and inappropriate treatment.

Baghirathan *et al.* (2018) reported the perceived "fear of diminishment" from the provision of the non-culturally orientated services that fail to accommodate the carers' need. Rabiee and Smith's (2013) study of black African and black African Caribbean carers found the effect of "social inequality" in the use of the available MH services in Birmingham. This was apparent in the concern carers highlighted the unsatisfactory provision of psychological therapies and the excessive amount of prescription administered to BAME patients. Rabiee and Smith (2014) added that carers encountered some negative experiences whilst in contact with MH services. These include the staff attitude, paucity of equity in resource accessibility regarding speech therapy, dearth of care continuity and social model of operation, being ignored, disregarded, criminalised and misunderstood.

Hatfield *et al.* (1996) reported that participants were dissatisfied that the MH staff were unaware of the importance of Asian culture and religion, which could have affected the uptake of the available MH services by MH carers and patients. Greenwood *et al.* (2000) reiterated that cultural and religious awareness should be introduced as part of the training required by the MH staff to ensure the appropriate use of valuable information and diligent discharge of responsibilities. In the same vein, Watson *et al.* (2019) found that the attitude of healthcare providers often presented a barrier to accessing support as providers were perceived to be extremely busy, were uninterested in perinatal MH problems and failed to recognise the women's symptoms or dismissed them. The study also found that Asian and

Black women were less likely to be offered treatment than White women and health care providers were perceived to discriminate against the women on account of their ethnicity.

Difficulties in seeking help. Islam and colleagues (2015) acknowledged that service users were given opportunity to access and receive adequate care and support from the MH services at the point of "crisis" when they could be at risk to themselves or others. This was achieved through exaggeration of presenting symptoms by their caregivers to the available MH services to gain the required support. Another crucial factor mentioned in this study was the dearth of knowledge and understanding of the GPs about mental illness and the type and appropriate services available to access, which thereby led to delay in accessing these MH services when needed by the service users. Furthermore, "Social stigma and shame" were other key factors mentioned that caused help-seeking delay among the participants.

Mukadam *et al.* (2011) and Mackenzie (2006) added that where stigmatisation was reported by the BAME carers as a barrier to using the MH services this stigmatisation was not encountered by the four white carers that participated in the study.

Islam *et al.* (2015) highlighted high turnover of staff as a negative factor owing to the changing of staff which affected the solid relationship built over time with the MH service staff. Islam and colleagues (2015) and Greenwood *et al.* (2000) noted that the inability to choose the gender of practitioners in charge of the care of the service users was another concern raised. Having a separate male and female ward and gender-specific health professionals in the MH services to promote the privacy of the service users (Greenwood *et al.*, 2000).

Racial equality must be promoted to avoid discrimination by improving the cultural and spiritual proficiency of MH staff through proper training and education (Lindsey *et al.*, 2003; Dura-Vila *et al.*, 2011). Therefore, focusing and designing MH service interventions specifically for BAME group might be much easier to implement than influencing changes on a cultural level (Daker-White *et al.*, 2002). This implementation could be achieved through the provision of valuable information, resources, staff training and cultural modification of services to specific needs of people (Mier *et al.*, 2010).

Regarding combating the language barrier and the confidentiality concerning the use of interpreters, it is important to ensure the MH interpreters should be aware about their duty of confidentiality and service users are well informed of the MH services confidentiality policies. This is because in most cases MH staff are untrained to work with interpreters (Tribe, 2009) and most interpreters have no MH training (Cambridge *et al.*, 2012), but a useful model of practice was highlighted by El Ansari *et al.* (2009) about the use of bilingual services. As well, interpreters should be well trained in dialectic complexity and cross-cultural incongruence of MH issues to ensure the effective delivery of care services (Koo, 2012).

Discussion

Themes emerged that summarised the experiences of caregivers with MH services, and these were consistent across all the identified studies. All identified themes were crucial and need to be addressed if relevancy of support and access to MH services is to be improved for BAME individuals. It is of utmost importance to raise the awareness of people from BAME backgrounds in the areas of MH literacy and support for individuals living with and managing MH conditions and the associated stigma (Memon *et al.*, 2016; Bignall *et al.*, 2020). This can be achieved by improving information about services and access pathways as well as by training health-care provider on how to develop tailored and culturally sensitive communication strategies and care tailored towards individual and culturally sensitive care (Lamb *et al.*, 2015; Memon *et al.*, 2016).

It is also recommended that culture-specific health education leaflets are tailor-made, produced to be inclusive of and accommodate the diverse languages of ethnic minority groups, deemed imperative if, translating, application of and understanding of what MH services have to offer is to be transparent for BAME carers and service – users (Bhattacharyya and Benbow, 2013). In this light, the Joint Commissioning Panel for Mental Health (2014) explained that ethnic inequalities cannot simply be explained in a disease context. Therefore, the panel advised commissioners to collect BAME experiences and outcomes to better understand the full impact of ethnic inequalities upon MH and well-being.

Paucity in cultural and spiritual understanding by health professionals can manifest negatively into stereotyping and labelling of the BAME groups hindering access to much-needed care (Corneau and Stergiopoulos, 2012). Therefore, racial equality must be promoted to avoid discrimination by improving the cultural and spiritual proficiency of MH staff through proper training and education (Dura-Vila *et al.*, 2011; Joint Commissioning Panel for Mental Health, 2014). Promoting MH services that acknowledge and seek to rectify the negative impacts of institutional racism, alienation and powerlessness; associated with being of non-white heritage should be prioritised (Prajapati and Liebling, 2021).

Strengths and limitations

- Papers that identified and acknowledged BAME MH carers and MH services were focused on, which resulted in 20 eligible studies for synthesis.
- We searched three electronic scientific databases accessible from the authors' institution.
- Whilst the study might have been limited by the search strategy applied, this does not diminish the relevance of our findings and the value added to knowledge.
- This review is limited to studies in the UK; the themes identified are widely relevant elsewhere in the world.

Conclusion

This review has revealed a variety of themes that influence the uptake of MH services and support by the carers as lack of understanding of some BAME carers about the available MH services and available support. Identified also are the impacts of fear of stigmatisation, discrimination and stereotypical nature of some MH services which hinder and cause delay in accessing the available MH support.

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